Introducing a model for emotional distress in respiratory disease: A systematic review and synthesis of symptom management models

Running title: emotional distress in respiratory disease

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Conflict of interest statement

The Authors declare that there is no conflict of interest.

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Abstract

Aim. To undertake a theoretical systematic review to develop a conceptual model of illness-related emotional distress in the context of symptom management in chronic respiratory disease.

Design. We performed a systematic search to identify conceptual models.

Data sources. Electronic databases MEDLINE, CINAHL, EMBASE and PsycINFO were searched and papers included from inception of the search term until June 2017.

Review methods. The review was conducted following Pound and Campbell's and Turner's theory synthesis. Conceptual models were appraised using Kaplan's criteria. Models were excluded if they referred to a specific condition and / or lacked clarity.

Results. This synthesis, which includes five models and additional evidence, yielded a new conceptual model describing the processes of regulation and symptom self-management in chronic respiratory disease. Identified sources of illness-related emotional distress are new or increased symptoms, additional treatment, new restrictions in performance of daily life roles and increased unpredictability. Patient goals and self-efficacy were identified as further drivers of symptom self-management. The regulation process is embedded in contextual factors.

Conclusion. Theory synthesis provided transparent guidance in developing a model to understand of the factors driving self-management decisions. Therefore, the model has the potential to guide development of interventions that support symptom self-management in chronic respiratory disease.

Impact. This newly presented conceptual model of illness-related emotional distress provides an understanding of the factors that drive self-management decisions when patients experience new or increased symptoms. Such understanding is critical for nursing practice to developing appropriate interventions, especially in support of patient decision making.

Keywords

systematic review, symptom management, respiratory nursing, nursing models, self-care, self-efficacy, emotions, adherence

INTRODUCTION

Symptoms in respiratory disease, such as breathlessness, are experienced as life-threatening resulting in high symptom distress and overall emotional distress (Giacomini, DeJean, Simeonov, & Smith, 2012). This may even affect long-term psychological outcomes. Thus, patients who experience severe deterioration of their chronic condition suffer increased levels of anxiety and depressive symptoms in the longer term (Man et al., 2015; Olveira et al., 2016; Quittner et al., 2014; Snell, Fernandes, Bujoreanu, & Garcia, 2014; Teixeira et al., 2015). Understanding the role of illness-related emotional distress in symptom self-management in respiratory disease is the basis to develop interventions to support patients' symptom management. Therefore, a conceptualization of illness-related emotional distress is urgently needed.

Background

Illness-related emotional distress has been reported as an independent factor in poor self-management and outcomes in chronic diseases. For instance, illness-related emotional distress was found to be correlated with poor self-management and poor glycaemic control in diabetes (Fenwick et al., 2016) and poor adherence to chemotherapy in cancer (Yee et al., 2017). In chronic respiratory disease, illness-related emotional distress is reported to be especially present and high if patients undergo an exacerbation of their chronic condition, which they experience as a change in their normal symptoms and deterioration of their condition (Schmid-Mohler, Caress, Spirig, Benden, & Yorke, 2018; Schroedl et al., 2014; Walker andrew, Hodson, & Roberts, 2017). Illness-emotional distress again affects symptom self-management and may be a key influencing factor for delayed help-seeking (Andersen, Thomsen, Bruun, Bodtger, & Hounsgaard, 2017; Schmid-Mohler, Yorke, Spirig, Benden, & Caress, 2018). Delayed help-seeking has been associated with poor clinical outcomes such as longer recovery time, increased risk of hospitalizations and poorer quality of life in COPD (Langsetmo, Platt, Ernst, &

Bourbeau, 2008; Wilkinson, Donaldson, Hurst, Seemungal, & Wedzicha, 2004). To foster symptom self-management, especially timely decision-making, the use of action plans is widespread in COPD care and shows generally good effect regarding health-related quality of life and hospitalizations (Lenferink et al., 2017). Despite this knowledge, poor adherence to action plans is common and multifactorial. Apart from a lack in knowledge, emotional distress - in the form of anxiety and depression - have been identified as risk factors for non-adherence (Choi, Chung, & Han, 2014).

Understanding the role of illness-related emotional distress in patient decision making and including this factor in interventions may have the potential to enhance the effectiveness of those most commonly used. The development of interventions should be guided by a theoretical framework, following a set of ideas that can be tested and further refined, thereby enhancing the effectiveness of interventions (Moore et al., 2015). To advance this knowledge, a conceptual model for respiratory diseases is needed, linking illness-related emotional distress with symptom self-management in respiratory disease.

THE REVIEW

Aims

Our aim was to 1) search and appraise currently available models for symptom experience and management and 2) synthesize the selected models into a conceptual model that links illness-related emotional distress with symptom self-management in chronic respiratory disease. We understand a conceptual model to be a theoretical framework that explains the relationship between a set of concepts and generally includes a schematic illustration of the relationship (Polit & Beck, 2012).

Design

A systematic literature search was applied using the BeHEMOTh (Behaviour of Interest, Health context, exclusions and Models / Theories) format. Identified models were appraised according

to Kaplan's criteria und only included if they fulfilled certain quality criteria. The selected models were then synthesized following Pound and Campbell's and Turner's theory synthesis.

Search methods

A systematic literature search of the electronic databases MEDLINE, CINAHL, EMBASE and PsycINFO, to identify conceptual models on symptom management was performed in May 2014 and updated in June 2017 and included all studies published from inception of the search term until June 2017. The search terms were defined according the BeHEMOTh format (Behaviour of Interest, Health context, exclusions and Models / Theories) (Booth & Carroll, 2015): In the first search, search terms included 'symptom management' (Behaviour of Interest) AND 'respiratory disease' (Health context) AND 'conceptual model' OR' theoretical framework' (Model or Theories). As we were not able to identify any relevant theory in this search, we broadened our search to generic models. So, in the second search, search terms included 'symptom management' (Behaviour of Interest) AND 'conceptual model' OR' theoretical framework' (Model or Theories).

A pre-search with the terms 'model* or theor* or framework* or concept*' yielded a high number of non-relevant search results (e.g. animal models, statistical models). Finally after testing several search strategies, the combination of the two terms 'conceptual model' OR 'theoretical framework' resulted in a high number of relevant studies. No exclusion criteria were integrated in the search strategy. We extended our systematic literature review with expert consultation (Noyes et al., 2016): We asked three experts for the names of empirically-tested symptom management models. Each expert has written, at minimum, a doctoral thesis in the field of symptom management.

Search outcome

Inclusion criteria were conceptual models that focused on symptom experience and / or symptom self-management. Exclusion criteria were conceptual models 1) that referred to a

specific condition or symptom and / or 2) that lacked conceptual clarity and consistency (after critical appraisal). Articles were included that 1) described the theory in their initial phase and 2) updates of the theory from the same author group.

Quality appraisal

The first author critically appraised the conceptual models according to Kaplan's criteria (Smith, 2014) which refer to focus, clarity, consistency and anchoring in empirical evidence (Table 1). Models were excluded if they lacked clarity and consistency: if they did not describe the phenomenon of symptom experience and management in detail, did not provide a definition of the main concepts (symptom experience, symptom management, outcomes and / or contextual factors) or did not present the relationship between the concepts within a logical model.

Data abstraction and synthesis

Synthesis was guided by the work of Pound and Campbell (2015), which is itself based on the approach proposed by Turner (1991). Theory synthesis – in contrast to metatheory - is a rather pragmatic approach, in the sense that the approach is concerned with synthesizing theories to inform daily practice. As a consequence, it focuses on the theories themselves and less on the underlying philosophical assumptions of the theorists (Pound & Campbell, 2015). In contrast to Pound and Turner, we took a deductive approach in summarizing the theories, as our aim was to understand the role of 'illness-related emotional distress' in 'symptom management'.

Our theory synthesis followed ten steps which were derived from the earlier work of Pound and Campbell and Turner (Table 2): In preparing the theories for the synthesis, each theory was summarised (Step 1) and themes that the theories had in common were identified. Then we extracted the aspects of the theories that referred to emotional distress (Step 2) and stated the relationship to the identified common themes. In this first step, a working definition for 'illness-related emotional distress' was developed, which was 'an umbrella term for uncomfortable

emotions such as anxiety, sadness and others, that arise from illness (such as treatment, symptom or meaning of illness)'. Thus, symptom distress was one aspect of illness-related emotional distress. In reviewing the empirical evidence regarding emotional distress and the relationship to concepts of the theory, we extracted key statement findings regarding emotional distress in the chronic respiratory patient population (Step 3). After breaking down the theories and empirical evidence using simple propositions on a common level of abstraction (Step 4), we reviewed points of similarity, convergence and divergence (Step 5). In the final phase, we combined the different elements from the theories and evidence into one conceptual model (Steps 6 and 7). As an added step to the work of Pound and Campbell and Turner, we included a review of the conceptual model by three experts (one clinical nurse specialist and two nurse scientists, one with special expertise in chronic respiratory disease). After review by three experts (Step 8), we refined the conceptual model (Step 9).

FINDINGS

Search outcomes

An overview of the literature search is provided in Figure 1. A total of 12 relevant conceptual models were identified. Four were excluded because they referred to specific conditions (Finnegan, Shaver, Zenk, Wilkie, & Ferrans, 2010; Mammen & Rhee, 2012; Parker, Kimble, Dunbar, & Clark, 2005; Spirig, Moody, Battegay, & De Geest, 2005). Of the remaining eight models, three were used as the basis for the development of the other five: these three were the Symptom Management Theory (Dodd et al., 2001; Humphreys et al., 2014), the Theory of Unpleasant Symptoms (Lenz & Pugh, 2014; Lenz, Pugh, Milligan, Gift, & Suppe, 1997; Lenz, Suppe, Gift, Pugh, & Milligan, 1995) and the Common Sense Model (Leventhal, Brissette, & Leventhal, 2003; Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Meyer, & Nerenz, 1980). The other five models used at least one of the previous three models as the basis for their development. This were the Symptom Interpretation Model (Teel, Meek, McNamara, &

Watson, 1997), the Symptom Experience model (Armstrong, 2003), the Symptom Experience in Time Theory (Henly, Kallas, Klatt, & Swenson, 2003), the Theory of Symptom Self-Management (Hoffman, 2013) and the Dynamic Symptom Model (Brant, Beck, & Miaskowski, 2010; Brant, Dudley, Beck, & Miaskowski, 2016).

Quality appraisal

The eight conceptual models were critically appraised using Kaplan's criteria (Smith, 2014) (Table 3). Three models, Symptom Experience in Time Theory, Symptom Interpretation Model and Dynamic Symptom Model, had limitations relating to quality due to the fact that not all concepts were clearly defined or presented in a fully logical model. It was not explicitly stated whether these three models evolved through scholarly inquiry and / or patient involvement. Given the lack of clarity, which is a premise for concept building, development of empirical indicators and further testing of the model, these were excluded. Therefore, five models were included in the review: Symptom Management Theory (Dodd et al., 2001; Humphreys et al., 2014), Theory of Unpleasant Symptoms (Lenz & Pugh, 2014), Common Sense Model (Leventhal et al., 1992), Symptom Experience Model (Armstrong, 2003) and Theory of Symptom Self-Management (Hoffman, 2013).

A major strength of the five included models was their clarity and consistency, with all concepts being defined at a middle range of abstraction and the relationship of concepts being logically illustrated within each model. A further strength was their anchor in evidence. All were underpinned by empirical evidence and, in each case, published examples of their use in practice or research were identified. An overall limitation of the models was that empirical indicators were not identified for all relevant concepts of the conceptual models, such as symptom experience, symptom self-management and outcomes. As a consequence, the models have not been validated in full, with only the operationalised concepts having been validated.

Empirical indicators were specified for symptom perception, self-efficacy and certain outcomes like health-related quality of life (QOL), as well as partially for influencing factors. Additionally, for symptom management strategies, empirical indicators were not identified in the Symptom Management Theory or the Theory of Symptom Self-Management. Those studies measuring symptom management strategies (Humphreys et al., 2014), mostly measure adherence or self-efficacy in performing a certain behaviour. As a consequence, only relationships between operationalised concepts were studied and no model has been validated as whole. Of the five models, none focused specifically on acute episodes and all had been empirically tested mainly in stable phases rather than during acute phases (Dempster, Howell, & McCorry, 2015; Humphreys et al., 2014).

Preparation of the synthesis

The preparation of the synthesis followed Steps 1 to 5, which were introduced in the method section (Table 2).

Preparing the theories. The summaries of the theories (Step 1) are presented in Supplement 1. Symptom experience, symptom self-management, outcomes of symptom management and influencing factors were identified as common themes of the five theories. The aspects of the theories that referred to emotional distress and symptom distress (Step 2) and the relationship to the identified common themes are described in Table 4.

Preparing the further empirical evidence. Four key statement findings regarding emotional distress in chronic respiratory patient populations were extracted from the empirical evidence (Step 3):

- Symptoms, treatment and unpredictability are the sources of emotional distress: Patients with COPD and CF report that deterioration in their chronic condition, e.g. pulmonary exacerbations, lead to high levels of illness-related emotional distress, whereby distress is due to increased symptom (Abbott et al., 2009; Korpershoek, Vervoort, Nijssen,

Trappenburg, & Schuurmans, 2016) and treatment burden (Sawicki & Tiddens, 2012). Furthermore, the unpredictability of the situation regarding the future adds to distress (Bailey, 2001; Harrison et al., 2014).

- The source and the total level of emotional distress guides decision making: Qualitative data indicates that exacerbation-related emotional distress does affect symptom self-management during the exacerbation. CF patients reported different dimensions of distress for symptoms, treatment and the overall experience during a pulmonary exacerbation that guided their symptom self-management during exacerbation (Schmid-Mohler, Caress, et al., 2018) and reported a close connection between fear and avoidant behaviour (Palser, Rayner, Leighton, & Smyth, 2016). Similarly in COPD, fear and perceived influence on the course of the exacerbation were reported as guiding symptom self-management (Korpershoek et al., 2016).
- Repeated experience of ineffective symptom management, which accompanies high symptom distress, leads to the feeling of powerlessness: The experience of uncontrollable symptoms leads to an overall feeling of powerlessness, helplessness and uncertainty in the longer term (Giacomini et al., 2012; Sheridan et al., 2011). These feelings were reinforced if patients underwent this experience several times (e.g. in form of exacerbations) (Tracy, 1997). Feelings of powerlessness during an exacerbation may lead to the belief that nothing helps control CF, which in turn may affect symptom self-management in the longer term (Sawicki, Sellers, & Robinson, 2011).
- Along with emotional distress, patent's individual life goals drive self-management decisions: Individual aims and goals have been reported as strong drivers for symptom self-management decisions. In CF and COPD exacerbations, patients choose self-management strategies that helped them to keep or reestablish normality (Korpershoek et al., 2016; Schmid-Mohler, Caress, et al., 2018).

Points of convergence and divergence of the theories and further empirical evidence. In bringing the theories and empirical evidence onto a common level of abstraction (Step 4), the following points of convergence and divergence were identified (Step 5):

The five models converge with recognizing symptom distress is the emotional aspect of symptom experience. It is expressed as 'bothersomeness', upset and / or suffering. Symptom distress is the result of a cognitive evaluation of the symptom, taking the severity and frequency of the symptom into consideration. The overall evaluation criteria is the meaning of the symptom(s). The meaning is formed by beliefs about the symptoms and includes the perception of restrictiveness in daily life and threat and control.

Illness-related emotional distress was not a term used in the five models. Each model included a conceptually related term: emotional status, mental state or mood, affective reaction, emotions or psychological state. They were either outcomes (Symptom Management Theory, Symptom Experience Model) or influencing factors (Theory of Unpleasant Symptoms) or moderating factors (Common sense, Theory of Symptom Self-Management) or outcomes of symptom experience or management. So, the models concur that emotional distress is a relevant component of symptom experience and management, but diverge on its placement. Empirical evidence in chronic respiratory disease highlights that illness-related emotional distress is a moderating concept between symptom experience and symptom self-management. In addition to symptoms, treatment is reported as a relevant stressor.

The relationship between symptom distress and emotional distress is described in the Symptom Experience Model whereby the meaning of the symptom or a symptom cluster contributes to emotional distress, not only on the symptom level but on a situational or even existential level. The perception of the symptoms is embedded in a broader, existential meaning which includes the patient's own perception of his or her vulnerability and mortality and contributes to illness-related emotional distress (Armstrong, 2003). Empirical evidence in chronic respiratory disease

is in line with the models, with important evaluation criteria being perceived threat and control of the illness situation as well as perceived restrictions in daily life due to the illness. It adds that symptoms and treatment are evaluated against these criteria, which results in symptom distress and treatment distress. Whereas symptom or treatment burden are the main source of emotional distress due to illness, the level of emotional distress is not restricted to symptom and treatment burden, but applies to the totality of experiences and their meaning (Davidson, Dracup, Phillips, Padilla, & Daly, 2007; Devins, Bezjak, Mah, Loblaw, & Gotowiec, 2006; Higham, Ahmed, & Ahmed, 2013; Knight & Emanuel, 2007). It shapes the person's experience of symptoms and influences the subsequent self-management treatment (Gazzaniga, Ivry, & Mangun, 2013).

The Theory of Symptom Management includes the concept 'self-efficacy' and states that an individual appraises the situation twice. Initially, the individual judges the potential harm that can be caused and then he or she assesses the potential to control the situation, whereby the assessment is influenced by the individual's perception of self-efficacy in managing the symptom (Hoffman, 2013, p. 21). Empirical evidence in chronic respiratory disease adds that repeated experience of ineffective self-management leads to the feeling of powerlessness, which may have an impact on self-efficacy negatively in the longer term.

Hoffman's work is based on the Social Cognitive Theory (Bandura, 1982, 1998), where symptom distress or treatment distress is not explicitly mentioned. However, it can be concluded that 1) low self-efficacy expectations in managing symptoms and treatment, 2) receiving or having to do treatment / therapy that is not believed to be beneficial or necessary, (indicating low outcome expectations), or 3) not achieving one's self-efficacy outcome expectations (e.g. improvement in symptom status) lead to symptom distress or treatment distress (Bandura, 1982, 1998; Resnick, 2014). Empirical evidence adds that patient goals are strong drivers in self-management decisions.

In summary, the five models focused predominantly on symptoms as a source of emotional distress. They highlight that patients appraise symptoms within an overall situational context of illness and life, attributing a meaning to the symptom but also to the overall situation. This overall meaning leads to symptom-related distress, but also to distress associated with the overall situation, referred to as 'illness-related emotional distress' in this new model.

Synthesis and refinement: The new model of 'Managing illness-related emotional distress'

The synthesis and refinement of the synthesis followed Steps 6 to 9 and resulted in a new model that offers an explanation of why illness-related emotional distress is of special relevance in acute episodes and how patients' experience of illness-related emotional distress affects symptom self-management decisions. The model is presented in the following paragraphs:

Most people with a chronic condition may not perceive themselves as ill if they have no symptoms, no new symptoms or do not perceive any disruption to their usual level of function (Benner & Wrubel, 1989; Selby et al., 2011). This perception changes if the condition exacerbates, cannot be controlled by the daily medical regimen and / or if normal daily life is disrupted (Corbin & Strauss, 1992; Reed & Corner, 2015). As a consequence, illness-related emotional distress increases substantially. Figure 2 illustrates the areas where emotional distress increases during non-stable phases and which areas lead to a substantial increase in overall illness-related emotional distress: symptoms, treatment, unpredictability and restrictions in daily life. Beside from illness-related emotional distress, patients may experience emotional distress also from non-illness-related stressors such as stressful life events.

INSERT Figure 2. Increase in regular level of emotional distress during acute phases

Based on the previously presented theories and further empirical evidence, we define '*illness-related emotional distress*' as the interaction between *symptom distress, treatment distress, distress due to restrictions in daily life roles* and *distress due to unpredictability*. *Distress due to unpredictability* involves the evaluation of the overall (illness) situation as regards feeling

threatened and perceived control. The definitions for each kind of distress are provided in Table 5.

A noticeable change in bodily symptoms or a measurable sign mark the start of the regulation process (Figure 3), whereby '*Bodily symptoms*' are defined as the experience of one or multiple bodily symptoms, including energy-related symptoms and '*Signs*' are measurable expressions of the medical condition such as fever, weight, lung function, blood sugar, or laboratory values. In contrast to the Symptom Management Theory (Dodd et al., 2001), perception in this new model forms before conscious or cognitive interpretation of the information. Therefore, dimensions here are severity, frequency and quality and emotions are not involved.

INSERT Figure 3. Regulation process of illness-related emotional distress during acute episodes

Patients evaluate the symptoms, signs and treatment. '*Evaluation'* is understood to be the meaning that the patient assigns to one or several symptoms as well as the overall situation (Armstrong, 2003). The evaluation of symptoms is formed by the patient's beliefs regarding identity, cause, treatability and consequences of the symptom or symptom cluster (Dodd et al., 2001; Leventhal et al., 1992). These beliefs frame the patient's evaluation of the predictability of the situation which itself is based on the patient's evaluation of how threatening or controllable the overall situation is (Hoffman, 2013; Leventhal et al., 2003) and the overall perception of restrictions in daily life and/or normality (Armstrong, 2003). This evaluation strongly influences the degree of illness-related emotional distress the patient then experiences.

The degree of distress has a powerful impact on which symptom self-management strategies, including coping and help-seeking strategies, will be chosen as a consequence (Leventhal et al., 2003). Based on perceived distress, patients decide whether to manage with or without the support of health professionals. The reaction includes a conscious or unconscious decision on how to proceed and as a result, includes decisions regarding which symptom *self-management*

strategies to implement. This decision is either made by the patient alone or in conjunction with his or her environment, e.g., family. Additionally, decision making is greatly influenced by a patient's *internal goals regarding outcomes* and his or her *self-efficacy* beliefs (Table 5): The patient chooses those symptom self-management strategies that will help achieve his or her aims and which he or she feels confident can be performed (Hoffman, 2013; Resnick, 2014). Based on clinical experience, patients often apply symptom self-management strategies to address the overall illness-related distress, instead of addressing one single symptom (Jarden, Nelausen, Hovgaard, Boesen, & Adamsen, 2009).

As mentioned above, goals regarding outcomes differ from patient to patient. Whereas the overall desired *outcome* is a decrease in emotional illness-related distress, which type of distress is most relevant may differ from one individual to another. It may be a reduction in symptom distress, treatment distress, or distress due to restrictions in daily life. An overall goal is to achieve distance from perceived threat and regain control, whereby the areas addressed may differ greatly (Gazzaniga et al., 2013), as described above. Illness-related emotional distress is very likely a proxy for other outcomes such as performance in life roles (Lenz & Pugh, 2014).

Patients evaluate the effectiveness of the various strategies in reducing distress. If the strategies are effective, distress stabilises and eventually decreases. If the strategies are not effective, distress increases. Whether effective or not, it has an impact on the degree of distress as well as the goals and self-efficacy beliefs of the patient and the resultant decisions regarding self-management strategies.

The self-regulation process is shaped by contextual factors. Based on Symptom Management Theory and Theory of Unpleasant Symptoms (Humphreys et al., 2014; Lenz & Pugh, 2014), these are distinguished as illness-related, personal, social and environmental factors. *Illness-related factors* include severity of the acute episode, treatment modality, severity of disease and comorbidities. *Personal factors* refer to habitual behaviour, past experience, self-management

skills, spiritual beliefs and goals in life. *Social factors* summarize social context, expectations from social context and the peer community. *Environmental factors include* working situation, living situation, access to a specialized health-care team and trust of the health-care team. These factors vary from patient to patient and explain the variation in the exacerbation experience between patients.

INSERT Table 5. Definition of concepts

DISCUSSION

Guided by theory synthesis, different perspectives on emotional distress were explored and synthesised into a new model which provides a comprehensive focus on patients' symptom management of acute phases in chronic respiratory disease, with illness-related emotional distress as the key concept.

Our new conceptual model shows a regulation process that begins with symptoms and treatment as stressors, which are evaluated in terms of their potential threat, controllability and potential for restrictions in daily life and which result in emotional distress. Patient symptom self-management, with reducing distress as its aim, is guided by the level of emotional distress, the extent of self-efficacy and the patient's individual goals. The new model describes the relationship between symptom perception, symptom self-management and outcomes, making it a promising framework both for analysing patients' self-management decisions in clinical practice and for underpinning interventions to support patients' symptom self-management.

Although self-efficacy has been described in research as an essential driver, it can be hypothesised that decisions taken in acute phases are more driven by patients' goals, as the disease and the treatment are routine matters and high self-efficacy is already a given. Patients reported organisational issues, ambivalence about treatment and avoidant coping as potential barriers (Goss, Edwards, Ramsey, Aitken, & Patrick, 2009; Shipman, White, Gysels, & White, 2009) indicating that goals may be a more important driver. The role of the various components

remains to be explored. A better understanding of the factors that contribute to decision-making in acute phases of chronic disease could help to develop patient-centred interventions while reducing negative outcomes and costs.

The literature review of conceptual models conducted using the BeHEMOTh format, resulted in a very high number of non-relevant studies, as previously reported (Noyes et al., 2016). We regarded the use of exclusion criteria as problematic as it may threaten sensitivity and has to be adapted for the different databases. Restricting our search approach to 'conceptual models' and 'theoretical framework' excluded irrelevant studies, indicating high specificity, but probably risked not identifying all relevant papers. To minimise this risk and take into account that theories may have been published in non-digital databases (such as books), we consulted experts in this field. However, future research should determine an appropriate combination of search strategies and provide guidance for an optimal balance between specificity and sensitivity in the literature search for theories.

Our theory synthesis followed the procedure by Pound and Campbell (2015) and Turner (1991) and involved nine of ten steps. This approach provided a transparent and feasible guidance for the development of a conceptual model that describes the role of 'illness-related emotional distress' in symptom management in chronic respiratory disease. In contrast to the method used described by Pound and Campbell (2015), we applied a combination of inductive-deductive approaches of synthesis and integrated further scientific evidence to describe the relationship between the concepts. The integration of theories with further scientific evidence led to the refinement of the position of 'illness-related emotional distress' and 'symptoms'. The model and its potential to inform clinical practice will be tested in a future phase. The development of a patient-reported outcome measure to assess illness-related emotional distress in respiratory disease is in progress.

CONCLUSION

Thematic synthesis provided valuable guidance for the development of a conceptual model of illness-related emotional distress and its role in symptom management in chronic respiratory disease. The new model provides an explanation of why illness-related emotional distress increases substantially when new symptoms arise or existing symptoms worsen and describes the drivers for symptom self-management. Understanding the regulation of this process provides a framework for developing and evaluating interventions that support patient's' symptom self-management in chronic respiratory disease.

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

2) drafting the article or revising it critically for important intellectual content.

* http://www.icmje.org/recommendations/

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Table 1. Appraisal criteria according to Kaplan (M. C. Smith, 2014)

Focus	Focus has relevance for nursing
	Theory can be applied to a variety of groups
Clarity and consistency	Assumptions specified and congruent with focus
	Substantive description of named phenomenon at middle range level
	Concepts are at middle range of abstraction
	Concepts are clearly defined
	No more concepts than needed to explain phenomena
	Concepts and relationship logically represented with a model
Anchor in evidence	Origins rooted in practice and research experience
	Theory has evolved through scholarly inquiry
	Theory has evolved through patient involvement
	Empirical indicators have been identified for the concepts
	Published examples for use in practice and research in general

Table 2. Steps in theory synthesis

Pound and Campbell (2015)	**Turner (1991)**	**Our approach**
Synthesis preparation: the clarification of existing theories	1. Evaluate the clarity and adequacy of concepts, propositions, and models.	1. Summarise the theory - in describing briefly the main concepts of the theory and the assumed causal pathway between the concepts.
The extraction of what is useful, plausible and relevant to the purpose of the synthesis (and summarisation of it)	4. Extract what is viewed as useful and plausible in a theory from what is considered less so.	2. Extract the aspects that refer to the core concept(s) – extract terms used, their definition (if available) and the explicit and implicit stated relationships to the concepts of the theory.
-	3. Pull together existing empirical (including historical) studies to assess the plausibility of a theory.	3. Search for empirical evidence (qualitative and / or quantitative) that describe the relationship of the concepts of the theory in the population of interest.
Synthesis: making theories comparable by breaking them down into simple propositions and rendering them abstract		4. State the concepts and the relationships in simple propositions (from theories and empirical evidence). Reframe and rephrase the propositions on a common level of abstractions.
Comparison of the theories for points of convergence and divergence	2. Suggest points of similarity, convergence, or divergence with other theories.	5. Suggest points of similarity, convergence and divergence.
Bring together those aspects that converge.	5. Synthesize a theory, or portions thereof, with other theories.	6. Combine those aspects that converge in one theory. State the points of divergence separately, discuss them critically. Be explicit where further need for clarification exists.
Synthesis refinement: Closer analysis of the synthesis product - including an examination of causal processes, with a view to generating further theoretical insights and a more robust theory	-	-
-	6. Rewrite a theory in light of empirical or conceptual considerations.	7. Rewrite the theory in light of empirical or conceptual considerations.
-	-	8. Ask experts to review the theory for clarity, coherence and closeness to the 'real world experience'
-	7. Formalize a theory by stating it more precisely.	9. Rewrite the theory and integrate the points that arose in the external review. In this

Pound and Campbell (2015)	Turner (1991)	Our approach
	8. Rewrite a theory in better language.	process, refine language – more precisely and understandably.
-	9. Make deductions from a theory so as to facilitate empirical assessment.'	10. Make deductions from the theory (e.g. patient-reported outcome measures, intervention development).

Table 3. Critical appraisal of the conceptual models identified in the literature search

	Focus has relevance for nursing	Theory can be applied to a variety of groups	Assumptions congruent with focus	Substantive description at middle range level	Concepts are at middle range of abstraction	Concepts are clearly defined	No more concepts than needed	Concepts logically represented with a model	Origins rooted in practice and research	Theory has evolved through scholarly enquiry	Theory has evolved through patient involvement	Empirical indicators for the concepts	Published examples
Symptom Management Theory	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	IVP	partly	yes
Theory of Unpleasant Symptoms	yes	yes	yes	yes	yes	partly	yes	yes	yes	yes	yes	partly	yes
Common Sense Model	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	IVP	partly	yes
Theory of Symptom Self-Management	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	IVP	partly	yes
Symptom Experience model	yes	yes	yes	yes	yes	yes	yes	yes	partly	NR	NR	partly	yes
Symptom Experience in Time Theory	yes	yes	yes	yes	yes	partly	yes	partly	partly	NR	NR	partly	yes
Symptom Interpretation Model	yes	yes	yes	yes	yes	partly	yes	no	partly	NR	NR	partly	yes
Dynamic Symptom Model	yes	yes	yes	no	yes	partly	yes	partly	partly	yes	NR	partly	yes

IVP = in validation process, NR = not reported

Table 4. Different theoretical perspectives on symptom distress and illness-related emotional distress

Conceptual model	Symptom Distress (Definition, relatedness to concepts)	Illness-related emotional distress	Evaluation criteria	Relationship between distress and Symptom Self-management	Relationship between distress and Outcomes
Symptom Management Theory (SMT)	Symptom distress is a result of a cognitive evaluation of symptom perceptions, including frequency and severity.	Illness-related emotional distress is not directly stated. Conceptually related term is 'emotional status', which is an outcome in this theory.	For symptom distress: • frequency and severity of the symptom • meaning of a symptom, which is formed by severity, cause, treatability and effect on life For illness-related emotional distress: Not reported	Strategies aim to relieve symptom distress, but also symptom frequency and severity. (In)effective symptom self-management impacts emotional status.	Improved symptom status (including symptom distress) is primary outcome. Emotional status is a secondary outcome.
Theory of Unpleasant Symptoms	Symptom distress is the emotional component of symptom experience and is the degree to which the individual is bothered by it. It is related to symptom severity, but is a distinct concept.	Not directly stated. Conceptually related terms are 'mental state', 'mood' and 'affective reaction to illness (e.g. of anxiety)'. They are seen as influencing factors on symptom perception. Outcomes (e.g. limitation in role) cause emotional distress. Emotional distress interacts with symptom experience.	For symptom distress: • Meaning, which can be formed by knowledge regarding the symptom • severity, (timing, quality) For illness-related emotional distress: Not reported	Symptom distress guides help-seeking.	Symptom distress is not an outcome, but a predictor for outcome. Symptom distress has a high impact on quality of life.

Conceptual model	Symptom Distress (Definition, relatedness to concepts)	Illness-related emotional distress	Evaluation criteria	Relationship between distress and Symptom Self-management	Relationship between distress and Outcomes
Common Sense Model	Not reported	Not directly stated. Conceptually related term is 'representation of emotions'. Emotional distress (e.g. fear) arises if a symptom represents danger.	For illness-related emotional distress: • beliefs: identity, cause, timeline, consequences, and control • perceived danger of the symptom	Based on the 'illness representation', goals for danger control are established and the resulting 'illness coping strategies' are undertaken. So, emotional distress can be seen as one driver for symptom self-management.	Degree of danger / fear is an outcome, which is one form of emotional distress
Symptom Experience model	Symptom distress is the degree of mental and physical upset and suffering. It is a result of the meaning of the symptom(s).	Emotional distress is a result of the individual's interpretation of his or her vulnerability and the overall situation. The meaning of the situation is affected by the meaning of the symptom(s).	For symptom distress • meaning of the symptom or a symptom cluster • impact on daily life For illness-related emotional distress: • patient's perception of his or her vulnerability and mortality	Not reported	One consequence of symptom perception is the psychological state. Consequently, symptom perception may cause emotional distress.
Theory of Symptom Self-Management	Symptom distress is a result of perceived threat and / or lack of control.	Not directly stated. Conceptually related term is 'affective reaction to illness'. It interacts with symptom perception (including symptom distress), self-	For symptoms and illness-related emotional distress: • perception of threat • perception of control, shaped by self-efficacy	Self-efficacy and perception of threat and control, both closely related to emotional distress, impact symptom self-management.	Not reported

Conceptual model	Symptom Distress (Definition, relatedness to concepts)	Illness-related emotional distress	Evaluation criteria	Relationship between distress and Symptom Self-management	Relationship between distress and Outcomes
		management and outcomes. Emotional distress is a result of perceived threat and / or lack of control. Emotional distress is reduced by high self-efficacy.			

Table 5. Definition of concepts

Symptom distress is the emotional response to one or several symptoms that a) cause patient-perceived substantial restrictions in daily life and / or b) have a dimension of threat and / or c) are out of the patient's control and / or d) cause new symptoms or aggravate existing symptoms that have a dimension of distress.
Treatment distress is the emotional response to one or several treatments or therapies (including treatment of symptoms and behavioural recommendations) that a) cause patient-perceived substantial restrictions in daily life and / or b) have a dimension of threat and / or c) cause new symptoms or aggravate existing symptoms that have a dimension of symptom distress or require additional treatment having one previously described dimension of treatment distress.
Distress due to restrictions in daily life roles is the emotional response to restrictions due to symptoms and treatments in daily life that are perceived as substantial from the perspective of the patient, whereby 'substantial' indicates a) a perceived threat of harm or b) harm in this area of life. Areas of daily life pertain to three areas: performance at work, restrictions in relationships and balancing illness-related and non-illness-related demands.
Distress due to unpredictability is the emotional response to the meaning the current (acute) illness situation has for the patient. It is based on beliefs regarding the identity, consequence and curability of the acute episode. These beliefs frame how a patient evaluates the predictability of the situation which in itself is based on the patient's evaluation of how threatening or controllable the overall situation is.
Internal goals regarding outcomes are the goals patients want to achieve with the self-management strategy (e.g. symptom relief or being with others) and to a great extent they drive the choice of the self-management strategy.
Self-efficacy is defined as a person's judgment about his or her ability to accomplish a given task, whereas a task in terms of symptom management can be seen as a self-management strategy, or behaviour. Whereas the perception of control refers to the whole situation in this new model, self-efficacy beliefs refer to specific self-management strategies.
Self-management strategies are behaviours (including cognitions) that deal with bodily symptoms, treatment and emotional distress. In terms of symptoms, their aim is to recognise, prevent, relieve or decrease frequency, severity, quality and emotional distress associated with the symptom. As regards treatment / therapy, their aim is to perform the

treatment in a manner which patients believe to be beneficial, effective and the least harmful.

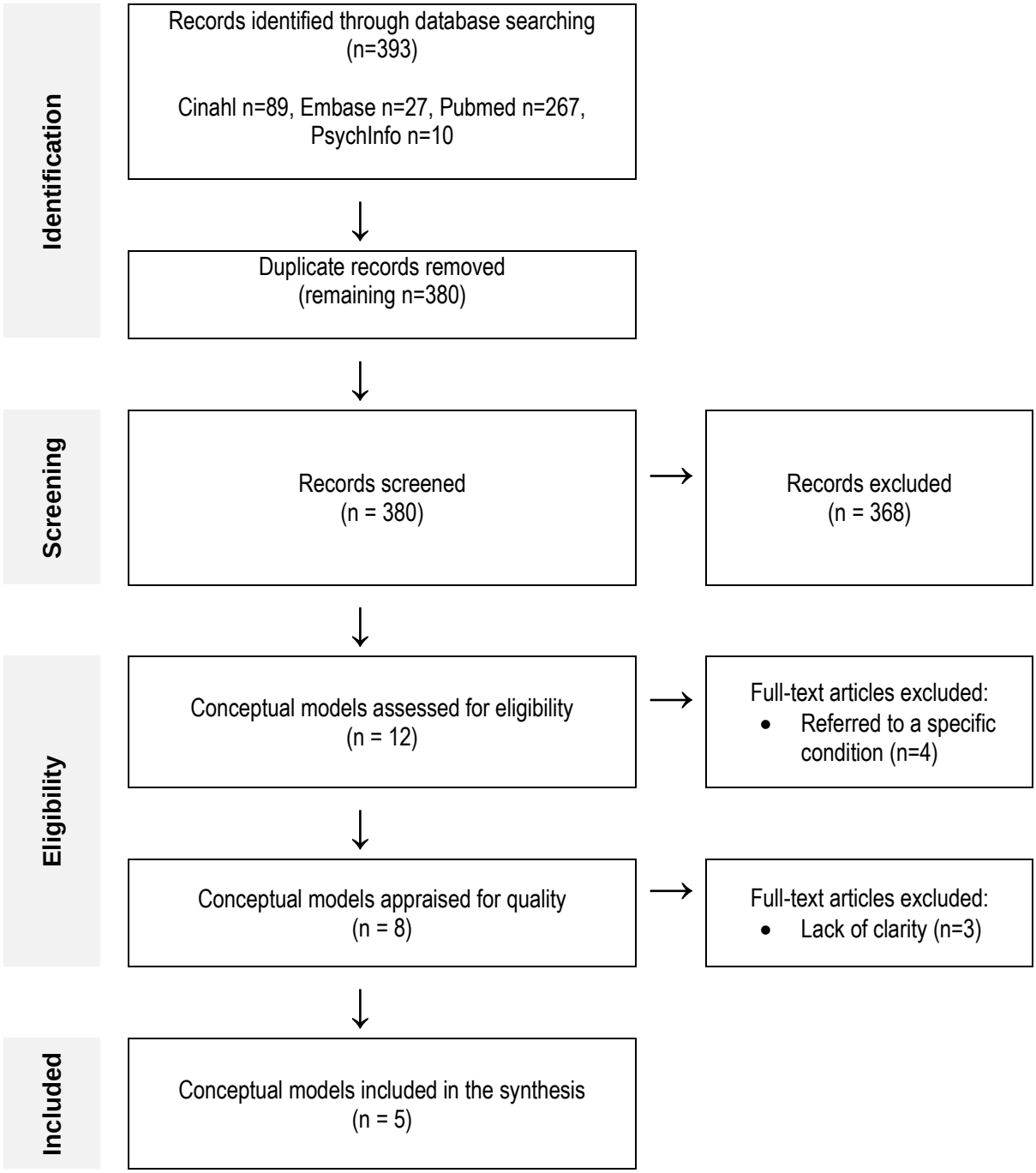

Figure 1. Flowchart of literature search for the conceptual models

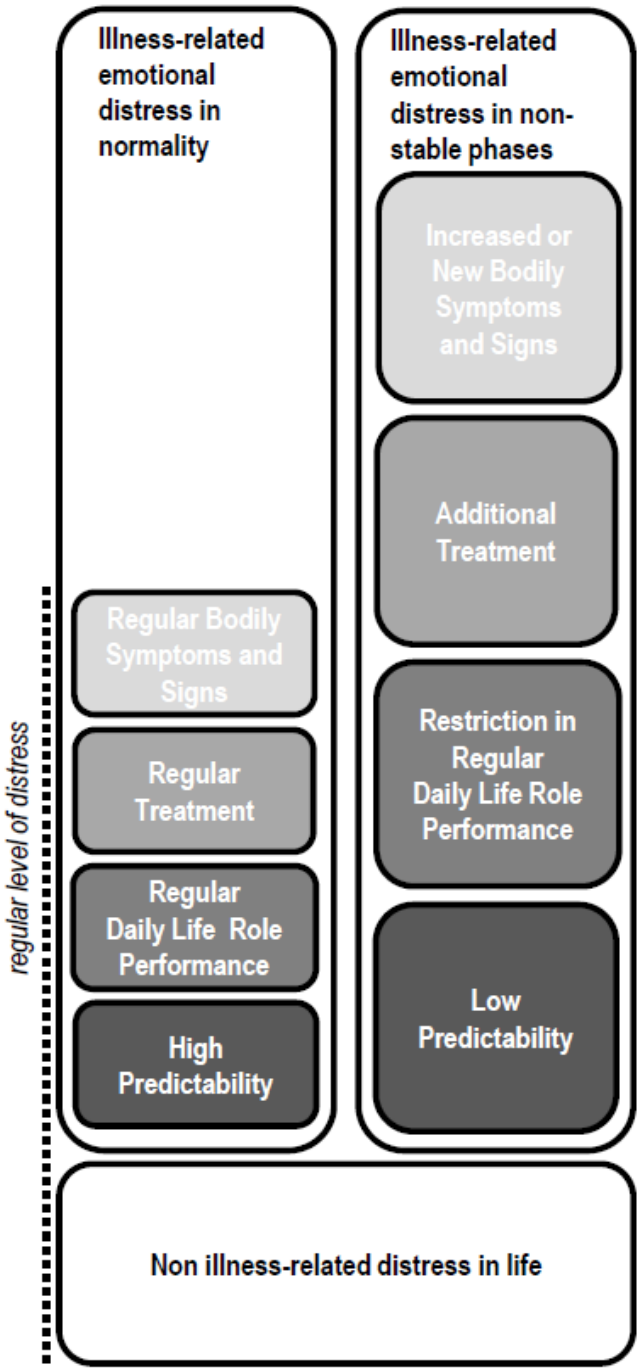

Figure 2. Increase in regular level of emotional distress in respiratory disease

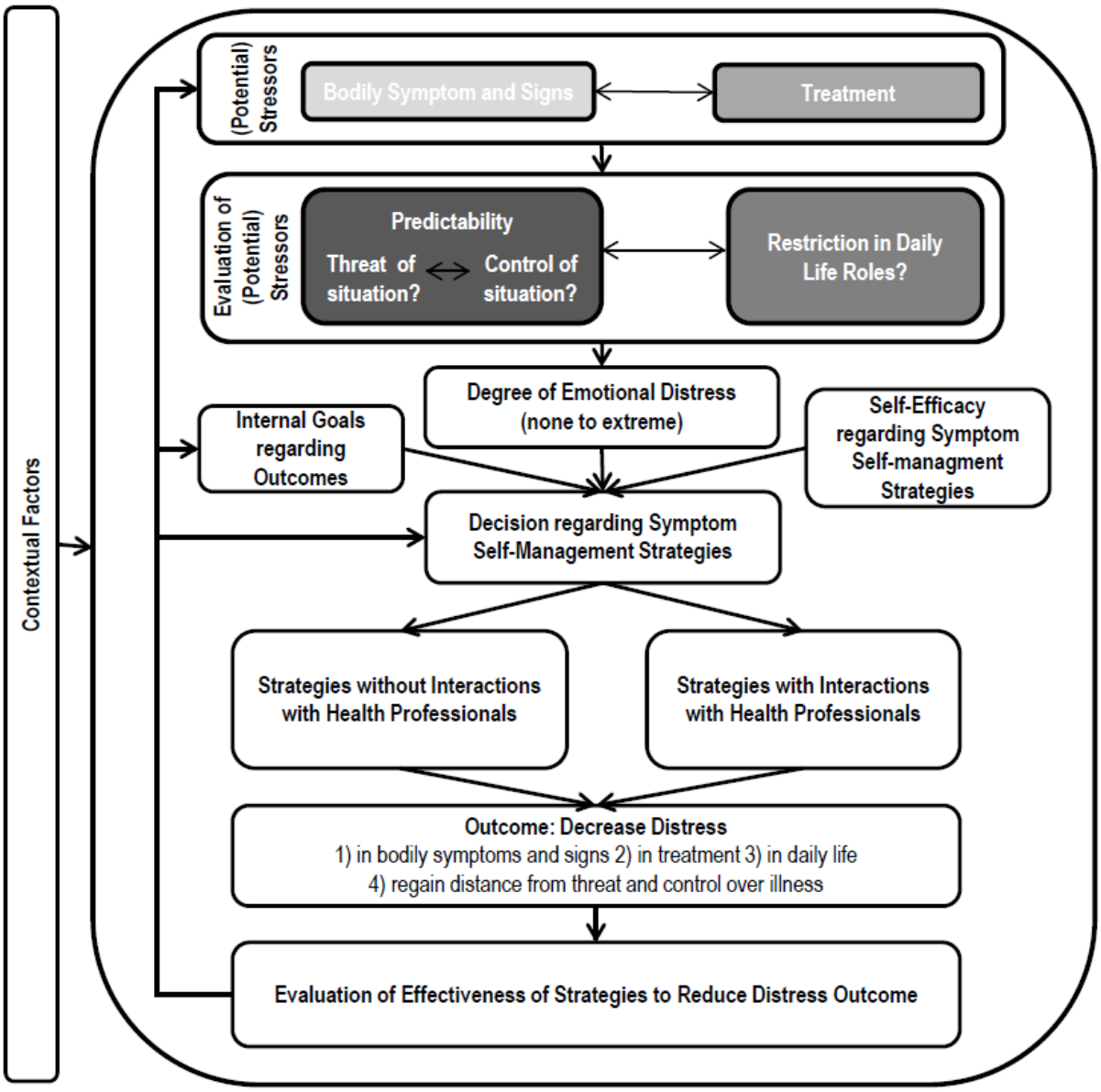

Figure 3. Regulation process of illness-related emotional distress in respiratory disease

Supplement 1: Summary of the theories

The Theory of Symptom Management (SMT) (Humphreys et al., 2014): The theory is based on nursing models such as Orem's self-care model and additional models from anthropology, sociology and psychology. It provides guidance on symptom assessment and treatment in nursing, and suggests questions and hypothesis for nursing research. The three main concepts 'symptom experience', 'symptom management strategies' and 'outcomes' interact simultaneously. This process continues until symptoms are resolved or stabilised. The process is impaired when adherence becomes a problem. 'The three concepts are influenced by contextual variables which are (1) person, (2) environment, and (3) health / illness.

The Theory of Unpleasant Symptoms (TOUS) (Lenz & Pugh, 2014; Lenz et al., 1997; Lenz et al., 1995): The theory was developed inductively from observation of the practice environment. It provides an understanding of symptom experience, especially of clusters, in various contexts and presents information on designing interventions. The core concepts are 'symptoms', 'influencing factors', and 'performance'. Three types of factors influence symptom experience: (1) physiological, (2) psychological and (3) situational, which interact with one another. Symptom experience can be one symptom, a combination, or an interaction of various symptoms. It has four dimensions: intensity or severity, distress, timing, and quality, all connected to each other. Consequences of the symptom experience are manifested in 'performance', the outcome concept. It includes physical and cognitive performance and performance in social roles. The experience of outcomes influences the symptom experience and its factors.

The Common Sense Model (CSM) (Leventhal et al., 1980), based on the work of other cognitive behavioural models: The model helps clarify adherence to regimen and the influence of cognitive factors on illness coping behaviours and outcomes (Leventhal et al., 1992). It is conceptualised as a parallel processing framework. The concept 'illness stimuli' impacts the cognitive and emotional 'illness representation' which comprises the following five domains 'identity, cause, timeline (duration), consequences (expected outcomes), and control (yes/no)' (Leventhal et al., 2003, p. 50). Based on the 'illness representation', goals for danger control are established and the 'illness coping strategies' chosen as a consequence, are undertaken. Those strategies impact 'illness outcomes' and 'appraisal'. A feedback loop begins, in which the appraisal of coping impacts stimuli, representation and coping strategy.

Symptom Experience Model (Armstrong, 2003): The model was developed based on the TOUS, the CSM and the work of Rhodes & Watson. Symptom experience involves symptom

production, perception and expression. It is influenced by antecedents (demographic, disease and individual characteristics) and produces consequences (e.g. adjustment to illness, QoL).

The Theory of Symptom Self-Management (TSSM) (Hoffman, 2013): The theory was developed based on the TOUS and the Theory of Self-Efficacy. It focuses on the impact of self-efficacy on symptom self-management. It includes the concepts ‘symptoms’, ‘perceived self-efficacy for symptom self-management’, ‘symptom self-management’, ‘performance outcomes’ and ‘patient characteristics’ as concepts, which relate to and interact with each other. The core concept in the model is self-efficacy, itself shaped by the experience of symptoms and interrelating with the patient’s characteristics and whichever interventions enhance self-efficacy. Self-efficacy has an impact on symptom self-management and consequently on functional and cognitive performance outcomes. The experience of those outcomes shapes self-efficacy in turn.